



MOUNT SINAI
SCHOOL OF
MEDICINE

Winter 2005

The MDA/ALS Beacon

The Muscular Dystrophy Association/Amyotrophic Lateral Sclerosis
The Mount Sinai Medical Center



Word from the Director

It is with great pride that I present you our second newsletter from the MDA/ALS Program at Mount Sinai School of Medicine.

This continues to be a work of devotion to helping patients and caregivers learn to live with ALS. Our contributing authors consist of professional staff, patients, and caregivers. We are saddened that one of the patients who enthusiastically supported us and taught us how to live every day to the fullest and shared that spirit in an article in this newsletter, Melvin Small, passed away while this Newsletter was in production. We extend our condolences to the Small family and we are grateful for what we learned from him and gain only more determination to conquer this disease.

There have been many changes since our last newsletter, both in our staff and our understanding of ALS through our research and clinical care. Our nurse coordinator, Lina Mina, RN, MEd welcomed a second son into her family. Nancy Xenakis, LMSW, MS our amazingly dedicated program coordinator and social worker, accepted a senior position in the Department of Social Work at the Hospital of Joint Diseases. Although she left physically, she has continued to work with us on various projects including the production of this newsletter. We also welcome Maura DelBene, MS, RN, NP-P, formerly the ALS coordinator at Columbia ALS Center and now the Nurse Practitioner in the Multiple Sclerosis Center at the Hospital for Joint Diseases. She has agreed to take over as facilitator of our educational support group and to assist us in the care of our patients. She brings an unparalleled experience in the care of patients with this disease.

Since our last newsletter, the FDA has allowed us to proceed with investigating a potentially new therapeutic agent, Disulfiram, to determine if it can slow the progression of ALS. The first phase which is to assess the safety of this drug in ALS patients, is under way. In another development, our collaborator, Guilio Pasinetti, MD, Professor, Molecular Biology, Mount Sinai School of Medicine announced at the International Motor Neuron Disease Association Conference, a potentially important biomarker that may give clues to better identification of patients with ALS and a better under

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Conversations with Caregivers: An ALS Nurse Clinician's Perspective

by Maura Del Bene, MS, RN, NP-P

In the past decade, I have been privileged to accompany patients and their caregivers on their journey of adjusting to, understanding why and trying to live with ALS. Because progressive muscle weakness requires the presence of another to continue performing to one's fullest capacity, even with the advances of medical technology, the caregiver is often the unsung partner in the relationship.

The emotional and physical energy spent organizing, planning and financing the care of a person with ALS is a full-time job, whether the caregiver is at work or at home part- or half-time. Insurance companies do not often place the necessary home health aide services in the home since the needs of the ALS patient are termed "custodial" and not "skilled". This leaves the caregiver with a tremendous amount of responsibility.

Here are some ideas to help caregivers and their loved ones with ALS maintain optimal wellness.

Emotional Support

- Seek out someone outside of the family to discuss your feelings and concerns with. It is often difficult to address these with the patient or another family member.
- Spend time on your interests and projects each week, even if it is only for an hour a week. Try to get others in your family or community to pitch in so that you can accomplish this goal.
- Include friends and family in the process so you and your partner have company and social interaction.
- Seek mutual support (peer guidance) through other caregivers, professionals, and support groups.
- Be honest with your loved one about your strengths and weaknesses as a caregiver. If you are proactive in this communication, there will be less stress between the two of you. For areas of weakness in caregiving, try to figure out how that task or area can be met in another way by another source.

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standing why ALS develops in some patients. These are indeed exciting times and we hope to build on these findings through continued research at this and our collaborating institutions.

Our staff remains dedicated to finding a cure for this disease as well as educating, caring, and helping ALS patients and their families in whatever way possible. In that spirit, we hope you learn and enjoy this issue of the MDA/ALS Beacon.

Dale J. Lange, M.D.

Director, Division of Neuromuscular Disease

Conversations with Caregivers

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Physical Support

- Attend Physical Therapy sessions and learn about the physical needs /techniques for the care of your loved one. This is often the best time to learn how care can be provided more efficiently or safely, interact with the medical team, and even sneak in some personal time.
- Use technology to accomplish your tasks. Often, medical equipment like a transfer board or hoist lift can alleviate the burden of physically lifting your partner.
- Make a videotape of addressing physical needs to show family or paid caregivers so you do not have to spend more time explaining the care style you and your partner prefer.

Financial Support

- Obtain information on your personal assets. This may not have been your role in the past, but it is essential for you to discuss finances with your partner so you are sure to be using all of your resources. It is always helpful to seek the assistance of a financial planner who can help assess your assets, as well as help prepare for the financial requirements an illness often brings (primary and secondary health insurance policies, wills, disability benefits/plans, advance directives, long term care insurance, family medical leave act, life insurance policies).

Take Care of the Caregiver

- Don't ignore your own physical health. This is often the most neglected area for caregivers. If you are not well physically how can you expect to provide care to another?
- Seek information early. Do not wait until you have needs that need to be met urgently. That is often the time when your options are fewer and your ability to make decisions is limited.
- Know your community resources (meals on wheels, community services, grants for personal assistance) and enlist friends and family to help, for instance with meals and laundry. The book *Share the Care* explains how to mobilize support.
- Take breaks (short or long) frequently. Replenish your emotional, spiritual and physical energy.
- Most importantly, **be realistic** in what you need to do and what you can do.

Work Together

- Discuss with your loved one the needs you each have. This is about both of you and it is a partnership of living and planning.
- Discuss the losses and "change in the road awareness". This is not where you expected to be in your lives. Figure out new ways to meet your goals and give them new time frames, discuss how you can do some shifting of goals and priorities.
- Most importantly, be proactive together. Stay ahead of the changes by working together, because this will promote better decision-making and fewer emergency situations.



"...When I think of my life, what it was, what it is, and what it was supposed to be, I find myself lost on the map [of my own life]. Why? Simply, Amyotrophic Lateral Sclerosis."

– ALS Caregiver



I am not sure how much longer I can do this. My life is so full in some ways and so empty in others. I love Jim but in a different way now than before. He requires so much attention and care and he only wants me, not the aides. I feel guilty with the boys not getting the attention they need from both of us and torn when I leave Jim to do something fun with them.

If I knew how long this would go on I could plan better but I also know I do not want Jim to ever leave us – isn't that terrible? Am I a bad wife for thinking like that?

– Maria 37, husband diagnosed with ALS for 4 years, mother of 2 boys (5 & 7 years old) & full-time office manager.



When Tom was diagnosed, we did not know a thing about ALS. As we learned more in the first few weeks the one thing we knew was that we had to have a partnership approach to his medical treatment. I stopped working, as did he and we spent time together. I knew his slurred speech was not going stay slurred and the thought of not having conversations with Tom scared me. As he did not want to use a communication device, patience was required to wait for him to write his thoughts and I become increasingly frustrated with not only those who could not wait but also Tom, as it would have been easier for us all if he just used a device. It seems also that as he speaks less he interacts less. Our communications are still there though, we talk in a way we never had time to before. In the evenings when the house is quiet, we look at each other, we hold hands and squeeze in different ways for different intentions or needs and the thoughts flow between us easier. I am grateful for that time as it helps heal the failings that I have in each day.

– Joan 69, husband diagnosed with ALS 2 years, retired with 8 grand children.

On Caregiving

This column is edited by Meryl Kauffman Houghton, primary caregiver for her husband, Dr. Alan Houghton who was diagnosed with ALS 12 years ago. Meryl regularly attends the MDA/ALS Educational/Support Group at Mount Sinai, conducts thorough research on resources for her husband, and has extensive caregiving experience.

Question: When is the right time to hire outside help and what is the process for doing so?

Answer: Do as I say, not as I do: Hire a home health aide as soon as you suspect you need one

We started talking about the need for a home health aide at least two years before we hired Cheryl. I was working full time, the boys were in elementary school, and Alan was (and still is) working full time. Mornings and evenings were times that the boys and Alan needed me simultaneously.

The sheer act of hiring an aide seemed more daunting than multitasking all of my responsibilities. Where to start? What type of person should I hire? What types of qualifications were needed? Agency? Privately? Notice that I said "I". Alan felt we needed more help, but never seemed to become involved. Though we desperately

needed help, it was easier to continue with the status quo.

A non-ALS emergency forced our hand. Alan came home from the hospital to find a lovely woman who had just entered the home health aide profession. Seven years later, Cheryl is still with us, preparing Alan for his busy workday. I look back to the pre-Cheryl years and wonder how I managed to get the boys off to school, help Alan get ready for work, walk him to work, and get to my own job on time.

We started talking about hiring an evening aide a few years ago. Though this time, I knew the type of care we needed, ways to locate aides, and the type of training required, again, I delayed hiring. It seemed less daunting to stay the course rather than spend weeks training another person. Also, adding another aide for four hours a day

meant another four hours of a non-family member in our home.

Again, a medical emergency forced our hand. Alan came home from the hospital to care by three different agency aides in five days. None were even remotely trained to deal with ALS patients. How would we train someone who may not be there tomorrow?

We stopped the agency aides and hired Mary, a woman recommended by a friend. Because she was highly skilled and experienced, it took less than a week before she was fully able to handle all of her responsibilities. What we didn't count on, however, was a non-stop ringing cell phone, a promptness and attendance problem, and constant intrusions of Mary's chaotic life upon her duties. Again, however, inertia took over and it seemed easier to keep her than repeat the hiring and training process with a new aide.

Six months after she was hired, Mary gave us two days notice and left to work in another profession. This time we put the emphasis on hiring a calm, mature aide with a stable personal life whom we would train to the level required for care of a person with ALS. By networking, through a recommendation of a friend, we hired a lovely, caring woman who we hope will stay with us for many years. Though it took about 6 weeks to fully train Elizabeth, knowing that we can rely on her brings calmness and serenity to our evenings.

Now, Alan talks of hiring another aide for a few hours on Saturdays and Sundays. With one son in college and the other joining him in September 2005, he feels I'll need additional relief. But the thought of training another aide seems so overwhelming that I think I'll wait a few months.

Do as I say, not as I do.

We look forward to answering your questions on caregiving. Please submit questions to The MDA/ALS Beacon at mda.als@mssm.edu or Box 1137, Mount Sinai Medical Center, One Gustave L. Levy Place, New York, NY 10029.

A Patient's Perspective: Easy Eating Tips

by Dorothy Kolb with Abbe Simon, M.A., CCC-SLP

To compensate for arm and hand fatigue while eating, Dorothy has developed an eating and feeding strategy that helps solve the problem of one's "mouth being too far from the plate." She has outlined a way to set up meals to foster independence while reducing the need for doing extra and exhausting "work."

Use a folding tray on legs (legs may be folded or propped, based on the height of your table and chair) and place it on a thick phone book, which rests on a straw placement to add a bit of height. Place a **hard** pillow under your dominant eating arm for support (firm pillows are also vital for reading/propping objects/pushing yourself up). Angle the pillow up a little bit so that one side partially rests on the tray. This raises and supports the eating arm by a couple of inches. The goal is to have your chin practically touching the plate. Switch arms if possible.

Tools that make eating easier are an iced-tea spoon (spoons can often be easier than a fork), a long curved handle with decent thickness, or a Styrofoam piece that has an insert for a utensil. An occupational therapist can use splinting material to make such devices and/or provide hand splints to support fatiguing wrists. It is extremely helpful to have your food cut up prior to feeding yourself. This reduces the amount of necessary work. Of course, hand-held foods (e.g., pita bread, slice of melon, sandwich, and banana) eliminate the need to raise your hand up and down as you do when using utensils.

Happy and Safe Eating!!

2nd Caregivers' Forum Hosted at Mount Sinai

by Nancy Xenakis, LMSW, MS

In honor of National Caregivers Month, the MDA/ALS Program at Mount Sinai hosted its second caregivers' forum on November 9. An expansion of the first such event in May 2004, the forum was designed to recognize caregivers for the important role they play—a tribute to all they do to enrich the lives of others. The event attracted caregivers from across the metropolitan area, receiving extremely positive feedback. Participants appreciated having a time and place specifically designed for them to relax, learn, and share.

Following opening remarks by Dale J. Lange, MD, caregivers participated in a choice of workshops (yoga, support group, massage therapy or reiki). The forum concluded with a presentation by The Rev. Dr. Kathleen Rusnak, MDiv, STM, PhD, titled "A Spiritual Perspective for Caregivers: Coping with Chronic Degenerative Illness."

We would like to acknowledge each of the wellness practitioners for donating their time and expertise and to Bonnie Sklar, Aventis Pharmaceuticals for providing the delicious refreshments for this forum as well as the monthly educational/support groups.

We hope to host another caregivers' forum in the near future. Please contact us at 212-241-6049 or mda.als@mssm.edu if you are able to provide support or would like to share your ideas.

"Friends of Claire" Event Raises ALS Awareness

My name is Claire Gormley Collier. I am a 42-year-old mother of three, who was diagnosed with ALS in October 2003. Although I have been faced with this horrific news, I cannot help but feel blessed to have some very special people in my life.

On Thursday, June 17, 2004, more than 600 people gathered to celebrate love, life and friendship. A committee of friends, who refer to themselves as "FOC'ers" (for Friends of Claire Foundation, Inc.) worked feverishly for eight weeks to coordinate the gala event. Proceeds benefit the Foundation, a Connecticut not-for-profit corporation dedicated to raising ALS awareness, funding research, changing policy, and helping with home modifications, home-care services and medical expenses.

In attendance to help spread the word about medical progress for ALS and other motor neuron diseases were Dale J. Lange, MD. Also present were Valerie and Meredith Estess, founders of Project ALS in honor of their sister, Jenifer, who lost her battle with ALS in December 2003. Project ALS has raised over \$20 million,

while bringing together doctors, researchers, and scientists from around the world to begin to find a cure for this devastating disease.

Since the Friends of Claire Foundation began, we have been overwhelmed by the numerous sources of support we have received. Family, friends, neighbors, members of our community, school, and church have all reached out to us at amazing levels. A golf cart was donated so I could be a part of our neighborhood activities. A six-year-old boy had a birthday party, and instead of presents, he asked all the children to make a donation to our Foundation — amazing! Angel medallions are being sold; we have had articles in local papers, magazines, and interviews by the local news stations. All this is helping our cause of raising awareness.

We have truly been touched by so many wonderful people and their acts of kindness. This helps the days pass with hope as we work and pray toward a cure.

For more information about Claire and the Friends of Claire's efforts:
E-mail: friendsofclaire@pop.net
Web site: <http://www.friendsofclaire.org>

MDA This Fall

by Leah Bailin

Over the past few months, the Association has been hard at work on projects to move forward with a cure for the disease as well as providing knowledge, support, and hope to those in the MDA/ALS community.

On September 29, 2004 members of the Wall Street financial community teamed up with MDA for "MDA's Wings Over Wall Street 2004" to benefit ALS research. The benefit, a cocktail reception at The New York Marriott Marquis in Times Square, featured live and silent auctions and was hosted by actor Billy Baldwin. Almost 1,000 people were in attendance, raising over one million dollars for ALS research.

The MDA also provides two monthly educational support groups for individuals and families dealing with ALS.

The ALS Educational Support Group, held in conjunction with the Eleanor and Lou Gehrig MDA/ALS Center at Columbia University, meets on the fourth Monday of every month from 6-8 pm at the All Souls Unitarian Church located on Lexington Avenue at 80th Street.

The MDA/ALS Educational Support Group conducted by the MDA/ALS Program at The Mount Sinai Medical Center is held from 6-7:30pm on the first Wednesday of every month in the Yahr Library (14th floor of the Annenberg building on the Mount Sinai campus). A light dinner and table of educational materials are provided. You can find a web listing and audio tapes of present and past groups at www.mssm.edu/neurology/neuromuscular/als or by calling 212-241-6049.

MDA is always eager to hear from those we serve. If you have any questions or suggestions, please feel free to contact Leah Bailin, ALS Health Care Service Coordinator at 212-689-9040 or newyorkcityalservices@mdausa.org.

Happy New Year!

Facing the Future

by Melvin Small

Note: Melvin Small died peacefully on December 4. His wife has requested that we publish this article as a tribute to his indomitable spirit.

I have always considered myself to be an active person. I loved to jog for miles, took interest in current events and had an open mind to learning new things. When diagnosed with ALS two years ago, I was taken by surprise.

I was an assistant manager with the NYC Housing Authority when I retired. My Teamster Union Local had a retiree program that offered classes in a variety of subjects and welcomed spouses. My wife and I joined an acting class, which gave performances at the end of the term, we signed up for a reading discussion group and took arts and crafts classes where we learned to paint, sculpt and create. I never knew I could be that creative until then. Not only did I learn, but I did so in a social atmosphere that has endured more than 14 years.

Now that I am not as mobile, I still look forward to the upcoming term and seeing friendly faces. Many stories can be told of various illnesses that friends have endured, but the

main thing I learned is the way each person has coped. Attitude, the will to do as much as we are able to, makes a big difference to the quality of life. Although I may not be able to be as physical, I can still participate in many other endeavors.

Several years went by before I found a neighborhood group that had meetings on timely topics such as electronic machines, Medicare, and Social Security. I have taken an active role at these meetings and helped with their organization by making phone calls, designing leaflets, etc. I recently joined a Social Action Committee at my local Senior Center, which is also interested in bringing issues that affect us to the public. If I can no longer go to my local union in Manhattan, I will continue with activities in the neighborhood.

While keeping busy is fun, I feel that seniors face an uncertain future that may result in loss of benefits. Recently, I joined with other seniors at a rally to defend our Social Security entitlement.

I am now using a wheelchair and movement is limited but as long as I can, I intend to participate as much as I can in life!

What's On Your Mind?

This column is written by Dorothy Kolb, Patient, The MDA/ALS Program, The Mount Sinai Medical Center.

This is a space for us to share our mutual concerns, frustrations, and our ideas about how to cope in our everyday lives. No subject is too small to be worth talking about.

I might start by describing some ways I've come up with for dealing with a few of the problems in doing the things that we used to do without thinking. Of course, what works for me may not work for you in exactly the same way (or at all), but at least it will be a starting point for you to find your own methods and, importantly, for a mutual conversation and exchange of ideas.

Question: I love to read but it's hard to hold a book and turn the pages. What can I do?

Answer: Prop the book on a hard pillow in your lap, or on a tray, or even on one of those boards with a pillow on the bottom that can also serve for lap writing. A rubber finger or the eraser end of a pencil helps to turn pages.

But here's an even a better idea:

Talking Books From The Library of Congress

This is a wonderful, free service, which—once your application is approved—provides a portable tape player and a seemingly endless selection of tapes of all kinds of books and periodicals. They have

a great phone service where you can request any book or request your favorite authors or category (fiction non-fiction, mystery, help books, new or old). Most of the readers are good, and you can even request by reader. The tapes are sent by mail and easy to return free in the same packaging. The player is, of course, on loan.

If the control buttons are hard for you to push, they will send a set of easy-to-attach levers that make it easier to play, go forward, back, etc. Turning the cassette over (4 tracks) might be awkward, but each side lasts for an hour or so.

I like to have it on the floor along side of the bed and since it's designed mainly for people with vision problems, it's perfect for listening in the dark!

Applications can be obtained from 800-342-3688. A doctor or other health care professional needs to authorize the need for this.

To express your reactions, contribute your thoughts and ideas, or pose a question regarding an issue that you need help with, please contact The MDA/ALS Beacon at:

Box 1137, The Mount Sinai Medical Center,
One Gustave L. Levy Place, NY, NY 10029
212-241-6049
e-mail: mda.als@mssm.edu

Visit Us Electronically

www.mssm.edu/neurology/neuromuscular/als and link to our message board.

It contains three forums:

- Educational/Support Group
- Questions Regarding our Services
- General Discussion

Clinical Research Studies at The Mount Sinai Medical Center

The following are clinical trials in which we are currently enrolling subjects. For more information please contact 212.241.8389.

- IVIG (Intravenous Immunoglobulin) in Lower Motor Neuron Syndromes (Motor Neuropathy)
- Multicenter Study Using the "VEST" (High Chest Wall Frequency Oscillation) in ALS
- The Safety and Tolerability of Disulfiram Treatment in ALS
- ALS Biomarker Studies

Helpful Reference Materials

Journals/Newsletters/Websites:

- Quest
- MDA/ALS Newsletter
- www.mdaua.org
- www.mssm.edu/neurology/neuromuscular/als
- www.mountsinai.org/msh/clinical_services/wecope
- Bob Broedel's online ALS Digest: to register: bro@met.fsu.edu, to review back issues: www.alslinks.com

Books:

"Creative Caregiving"

by James Sherman

"Humor for Healing: A Therapeutic Approach" by Linda Harvey

"The Magic of Humor in Caregiving"

by James Sherman

From the MDA:

ALS: Maintaining Mobility

ALS: Meals

ALS: A Caregivers' Guide

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